

HIV/AIDS

WORK GROUP ON

HEALTH CARE ACCESS ISSUES

for Gay and Bisexual Men of Color

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HIV/AIDS

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Overview

The Health Resources and Services Administration (HRSA), Bureau of Health Resources Development (BHRD), sponsored a Work Group on Barriers to HIV Care for Gay and Bisexual Men of Color on August 5-6, 1993 in Washington, D.C. Nineteen African American, Asian/Pacific Islander, Latino/Hispanic and American Indian/Alaska Native participants and four Federal representatives met to discuss barriers to obtaining HIV/AIDS services. The participants, from diverse backgrounds, experiences, and regions, were selected because of their knowledge of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, their participation in its implementation, or their involvement in identifying HIV care needs themselves. This group included policy makers, advocates, people living with HIV, experts in the evaluation of HIV/AIDS services, and service providers. While this group, because of its size and composition, can only partially represent the regional, cultural, and socioeconomic diversity of this nation, members shared a commitment to improving access to HIV care for gay and bisexual men of color and provided thoughtful insights on their experiences.

The goals were ambitious for a two-day meeting. HRSA asked work group participants to: identify barriers encountered by gay and bisexual men of color when using or attempting to use HIV/AIDS services; discuss the types of technical assistance needed to overcome these barriers; and develop potential questions for the evaluation of HIV/AIDS services. A central expectation was that the participants could help the agency identify technical assistance issues, evaluation topics and methodologies, and conceptual frameworks.

The work group decided to use a four step process to reach decisions about the issues and topics of concern to all participants. Following an initial brainstorming discussion that centered on access-to-care issues, four small groups met for in-depth discussions on selected issues. The groups established priorities and drafted evaluation questions.

Each of the four small groups prepared a list of priorities related to their topic. The entire work group then divided into four racial/ethnic groups (African American, Asian and Pacific Islander, Latino/Hispanic and American Indian/Alaska Native) to discuss the specific issues relating to their respective communities. The entire group then reassembled to

hear the reports and summarize the priorities. At the end of the second day, Federal officials with responsibilities for AIDS programs and representatives from national AIDS organizations joined the work group. This gave the work group an opportunity to share their views on the issues and to receive feedback on their activities.

This report summarizes the purpose of the work group, the issues identified during the initial brainstorming session, and the roundtable discussions of the topical and racial/ethnic groups.

Objectives

This work group is one of a series of meetings convened over a three-year period by the Office of Science and Epidemiology (OSE) and the Division of HIV Services (DHS) within HRSA's Bureau of Health Resources Development (BHRD). The primary objective of each meeting is to understand—from the point of view of underserved populations and those who serve them—the barriers to providing and obtaining HIV clinical and support services. Insight gained from these meetings about the availability, accessibility, and acceptability of specific medical and support services will assist BHRD in evaluating the CARE Act and providing effective technical assistance to grantees delivering services to people with HIV.

The idea for a work group on barriers to care for gay and bisexual men of color grew out of a concern about the disproportionate effect of HIV in ethnic and racial communities and a desire to identify the problems of delivering services to those affected communities, particularly those that have been historically underserved. Specifically, the work group members were asked to help BHRD:

- Understand issues related to CARE Act-funded access to HIV/ AIDS care for gay and bisexual men of color;
- Propose and draft evaluation study designs related to these issues;
- Identify areas for technical assistance to improve the delivery of services to this population.

In addition, the work group was asked to identify, as potential consultants, health service researchers working on topics related to HIV/ AIDS, members of affected populations, and individuals who deliver health care and support services. The group also was charged with suggesting methods and strategies for systematically assessing the effectiveness of the CARE Act in bringing emergency relief to gay and bisexual men of color who are affected and infected by HIV disease.

The Ryan White CARE Act

In 1990, as a response to the critical need to provide basic medical and support services for people living with HIV disease, Congress passed the Ryan White Comprehensive Resources Emergency (CARE) Act. The CARE Act became law on August 18, 1990 and received its first appropriations in November 1990. The principal objective of the legislation is "...to provide grants to improve the quality and availability of care for individuals and families with HIV disease..."

Titles I and II of the CARE Act are administered by the Bureau of Health Resources Development (BHRD), part of the Health Resources and Services Administration (HRSA). Grant funds, under Titles I and II, are awarded to chief elected officials (CEOs) of Eligible Metropolitan Areas (EMAs) most heavily affected by the HIV epidemic (Title I) and to CEOs of all States and U.S. Territories (Title II). The grants are used primarily to fund ambulatory, outpatient, and community-based care. This care includes both medical and social support services for individuals and families with HIV and AIDS who are underserved, underinsured or who lack critical services.

The CARE Act is founded on two basic tenets: (1) that people and communities affected by the HIV epidemic be included in planning and setting priorities and in managing the provision of care; and (2) that the comprehensive care needs of individuals with HIV and AIDS be met through a continuum of planned and coordinated services.

Despite these tenets and the requirements of the CARE Act, BHRD recognizes that there are barriers that limit or prevent underserved populations from receiving and, in some cases, even from seeking care. Many of these barriers existed before the HIV epidemic; most have been highlighted and/or exacerbated by it.

To identify these barriers and begin to develop plans of action for overcoming them, the work group meetings were developed to assist BHRD in defining the complex issues that influence use of HIV care, and to understand clients' perceptions of the availability and accessibility of specific medical and support services. The work group discussions were planned to focus on the difficulties faced by underserved populations with HIV disease: those people whose ethnic, racial, economic, gender, or cultural backgrounds differ from those of the population traditionally served by the medical clinics and social support agencies providing the

majority of HIV-related services. Each meeting addresses the critical access issues for one particular population.

The goal of these meetings is to define the difficulties these populations encounter and to identify strategies for ensuring that appropriate CARE Act services are made available to and utilized by them. In addition, some specific objectives for each work group are to:

- Develop priorities for evaluation research and specific evaluation projects designed to better understand the real and perceived barriers faced by unserved and underserved populations needing HIV/AIDS services;
- Compile a bibliography on barriers to HIV/AIDS care and related health services research;
- Identify health services researchers working on HIV/AIDS related topics; and
- Identify members of the affected population, as well as individuals who deliver health care and support services, who can serve as consultants and help identify priority issues for evaluation and followup.

The work groups also propose recommendations on specific mechanisms, including technical assistance from BHRD, for addressing the critical needs identified in their discussions.

Each work group is composed of between 10 to 20 invited participants representing the ethnic, minority, or special populations being addressed; they include service providers, people living with AIDS, and health services researchers. Work group meetings are two days in length, are moderated by BHRD staff, and are structured along informal lines to allow for creative thinking and in-depth discussion.

At least seven work groups on access to HIV services will be held through 1994. Five groups already have met to discuss the special access to care issues pertaining to African Americans, Hispanic Americans, Women, American Indians and Asian and Pacific Islanders. Additional work groups are planned.

This report focuses on the discussions, findings, and recommendations of the Gay and Bisexual Men of Color Work Group, held August 5-6, 1993. Men from four racial/ethnic communities were invited to participate, including individuals with HIV, service delivery professionals working with clients, and health services researchers with expertise in HIV and gay men's health. The meeting was co-facilitated by

BHRD staff member Moses B. Pounds and Christopher Bates, D.C. CARE Consortium. Individuals from Federal agencies and the private sector with an interest the health of gay and bisexual men of color and in HIV in general attended the final session of the meeting, during which proposed study designs and general recommendations were presented.

The work group's recommendations have been distributed to the participants for review and comment; these comments were considered in revised drafts. The final summary will be disseminated to Title I and II CARE Act grantees prior to the development of a final evaluation and program agenda. These work group meetings represent the beginning of a collaborative learning process among HRSA, its grantees, and people with HIV disease, whom these groups are dedicated to serving.

Background

"Across the United States gay men of color are being infected with Human Immunodeficiency Virus (HIV) more often and dying from Acquired Immunodeficiency Syndrome (AIDS) faster than their white counterparts. All across the country stories abound of gay men of color who have felt rejected by their own racial/ethnic communities. The appearance of HIV disease in the white gay community has left many gay men of color 'out of the loop.' The relative success that the gay community as a whole has experienced in preventing the spread of HIV has therefore not been mirrored in the rate of new infections among gay men of color."

(H. Alexander Robinson, 1993)

Since the beginning of the epidemic, HIV has affected people of color through the same modes of transmission as other populations. However, across the spectrum of the disease, HIV disproportionately affects gay men of color. The first report of AIDS in an African American man was June 1981. By August 1991, one in nine of the reported homosexual males with AIDS was African American.¹ As the National Commission on AIDS report stated, "Unquestionably, HIV/AIDS has hit the African American community hard...If one speaks about injection drug users and AIDS, one is speaking about people in the African American community. Similarly, if one speaks about gay men and AIDS, one is speaking about African American men, since roughly half the African American men who are infected are men who have sex with other men."

Sixteen percent of adult male reported AIDS cases has occurred among adult males in the Latino/Hispanic community, although this group comprises only nine percent of the total population. Although Asian and Pacific Islanders account for 0.7 percent of adult male reported cases, the service needs of gay and bisexual men from the Asian and Pacific Islander communities are important because 81 percent of these men with AIDS have sex with men, compared to 61 percent for all races/ethnic groups combined. Gay and bisexual men with HIV/AIDS from

1 National Commission on AIDS. (1992). *The Challenge of HIV/AIDS in Communities of Color*. National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003.

American Indian and Alaskan Native communities also are disproportionately represented.²

As described earlier, the intent of the CARE Act of 1990 was to respond to the needs of people in such communities by providing additional resources for medical and support services for people living with HIV and AIDS. While the intent of the law is laudable, segments of the recipients' communities have reported that the Act is not working for them. They feel that the services they receive are unacceptable and/or funds are insufficient to support existing or new services. Medical and health delivery systems often are not part of the unserved and underserved communities and are not staffed by members of those communities. Specifically, many gay and bisexual men of color, nationally the largest proportion of people with HIV disease, believe that they are not receiving adequate funding, services or representation in decision-making.

2 Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, June 1994, Vol. 6, No. 1.

Key Issues

During the two days of discussions, work group participants emphasized that their experiences differ from those of white gay and bisexual men. In addition to differences in socioeconomic status, most men of color identify themselves first as members of a racial/ethnic group. Unlike white gay and bisexual men, their sexual orientation may or may not be their primary identity or point of reference for their social or political activities.

Gay and bisexual men of color generally remain “invisible” within their racial/ethnic communities. A “don’t ask, don’t tell” philosophy is often the terms for acceptance and support from family, friends, and neighbors. Men of color frequently are rejected and alienated by the mainstream gay and bisexual society and organizations. Gay and bisexual men of color lack their own institutions to provide support and care, leaving them with fewer service options. Few of these men participate in the mainstream gay and bisexual political movement. Those who do often struggle to reconcile the issues of racial and ethnic identity. This conflict forms the context for health care delivery for gay and bisexual men of color.

The work group participants described specific cases in which members of white gay and bisexual communities practiced the same forms of racial discrimination fostered by the majority society. This has led to alienation and hostility between white gays/bisexuals and gays/bisexuals of color. To eliminate the common barriers, participants felt that a unified effort between gay and bisexual men of color was needed. They felt it was critical to find relevant and effective strategies for addressing HIV/AIDS-related social and service needs of this entire population, as well as to identify barriers that are culturally or ethnically specific to the various communities of color.

Four themes emerged from the two days of discussion: continuity of services, cost of services, institutional capacity, and leadership. The group identified cross-cutting issues related to these broad themes and each racial or ethnic group identified other issues that were specific to its group.

Cross-Cutting Issues. Across the ethnic groups, participants stressed that most gay and bisexual men of color preferred to frame their HIV care issues in terms of ethnic identity rather than gay or bisexual political

affiliations. This primary identification reflects the source of social, psychological, and economic support that gay and bisexual men of color receive from their families and communities.

Participants voiced concern about barriers experienced by ethnic community-based organizations (CBOs) when applying for HIV care funding due to their limited capacity and experience. Yet, many minority CBOs have greater credibility with and understanding of their people with HIV than do most mainstream providers. Work group members felt that the development of stable and sustainable HIV service agencies within ethnic/racial communities is essential to delivering effective, culturally competent, and prejudice-free services across the continuum of care to gay and bisexual men of color. To accomplish this objective, local grantees need to invest in infrastructure development within such CBOs and to provide appropriate technical assistance to them. Committed and motivated community-based agencies often have difficulty in making the transition from start-up organizations to mature organizations with sound management, financial, and advisory structures.

Participants stressed that gay and bisexual men of color are a diverse group for reasons other than race/ethnicity. To be effective in providing HIV services to this group, there must be varied and multiple points of access. Effective outreach efforts to bring gay and bisexual men of color into care and to keep them in care must reflect the wide range of literacy, languages, and cultures within this population. The fundamental element of all HIV service programs must be cultural competency and linguistic appropriateness. By grounding programs within ethnic and racial cultural values, local empowerment can be promoted and effective institutions developed.

African American Issues. Mistrust of government programs is based on a legacy of betrayal and tragedies, such as the Tuskegee Syphilis Experiment. Within African American communities, there is widespread suspicion that the HIV epidemic may have been intentionally introduced into their populations in the United States and Africa. In addition, there is the perception that the research establishments do not seriously consider KEMRON®—widely thought of as an African therapeutic—as a possible treatment for HIV.

Asian and Pacific Islander Issues. While numerically small, this group may be the most culturally, linguistically, and geographically diverse. Ironically, the public's perception of Asians as "model" minorities often results in a lack of public policy attention or

inappropriate policies that do not meet the needs of the underserved within Asian and Pacific Islander communities. Sufficient skills to respectfully and effectively address the concerns of people with HIV and their families rarely exist outside specific Asian and Pacific Islander communities. Therefore, HIV services must be integrated into other cultural responses to illness and disease and into community-based health and social service agencies that have the confidence of their members and the essential cultural and linguistic skills.

Latino/Hispanic Issues. Agencies delivering services to Latino/Hispanic people must have Spanish speaking staff who are knowledgeable about the diverse Latino cultures. Strategies that require individuals to “integrate” themselves into a mainstream organization will not appeal to Latinos/Hispanics, who prefer organizations and staff from their own communities. Also, it is important to acknowledge the importance of indigenous remedies to many Latinos/Hispanics and to integrate them into the continuum of HIV care for these populations.

American Indian and Alaska Native Issues. American Indians and Alaska Natives (also self-described as “First Nation” people) living with HIV too often fall between the cracks in the health service system. There is widespread confusion about who is responsible—the Indian Health Service (IHS), other Federal agencies, or State and local jurisdictions—for delivering HIV services to these populations. Despite the commonly held assumption to the contrary, the IHS is, neither legally nor practically, the exclusive provider of health care for First Nation people. Many American Indians/Alaska Natives living with HIV reside or spend a significant portion of their time in urban areas where IHS facilities or contract clinics are scarce. Another barrier to care for these individuals is the fact that they may reside in areas that span several local or State jurisdictions, each with different eligibility requirements. In rural areas and reservations, denial and the stigma of HIV as a white disease undermine timely health/help seeking. Finally, effective outreach to First Nation people with HIV must acknowledge and respect their cultures and traditions.

Charge from HRSA to the Work Groups

HRSA charged the work group with identifying behavioral and organizational factors that create barriers to the effective provision of HIV/AIDS health care and related support services for gay and bisexual men of color. Specifically, participants were asked to:

- Identify strategies and design evaluation studies of approaches to increase access to care for gay and bisexual men of color;
- Develop priorities for evaluation research on barriers to care;
- Develop strategies to increase participation of gay men of color in all aspects of decision making;
- Develop strategies to facilitate the inclusion of gay and bisexual men of color in the local and national decision-making processes for CARE Act funding; and
- Develop policy recommendations for effective program implementation within these target communities.

At the outset of the work group process, members of the work group expressed several concerns:

- How will this exercise fit into other evaluations and reports that HRSA has developed?
- How will the results of this activity improve access to services or programs for gay and bisexual men of color?
- How will the results be used to increase representation in the power structure or to deliver better and/or more services to gay and bisexual men of color?
- Is HRSA committed to challenging planning councils and consortia to achieve acceptable representation from gay and bisexual men of color?
- What is the work group's role in terms of monitoring and participating in this process?
- How will the results of this exercise address the needs of gay and bisexual men of color in rural areas and/or low prevalence areas?
- Beyond the evaluation studies that will come out of this work group, what recommendations will inform technical assistance and project management?

HRSA Perspective

Dr. G. Stephen Bowen, Director of the Bureau of Health Resources Development, and Dr. Eric Goosby, Director of the Division of HIV Services, responded to these concerns by stating that HRSA is committed to improving access to care for disenfranchised populations throughout the country. The agency works with the grantees to evaluate the CARE Act implementation process for various populations and to realize its goals. The intent of the legislation is to improve community involvement in the organization, planning, delivery, monitoring, and evaluation of HIV/AIDS service delivery and care. Special problems and issues related to gay and bisexual men of color, such as access to acceptable and respectful health care and participation in decision making, are of concern to HRSA. HRSA expects to use the perspectives of people living with HIV/AIDS (as identified in this work group and previous work groups) to improve the program.

Using a mechanism of well-designed qualitative and quantitative evaluation studies, HRSA can look more closely at the effective strategies for change identified by the work group. In addition to helping design evaluation studies, the agency plans to consult with members of this group, as well as other gay and bisexual men of color living with HIV, for advice on successfully conducting technical assistance. Previous access work groups have stated that grantees and providers often can improve the experiences of seeking treatment by creating an environment that is welcoming and respectful of the diverse populations of people with HIV disease. The agency will work with gay and bisexual men of color to assist CARE Act grantees in improving the care environment and increasing client satisfaction with CARE Act services.

Summary of the Initial Brainstorming Session

A roundtable discussion was held to “brainstorm” and develop a general list of issues, concerns, and topics central to overcoming barriers to services for persons of color who have HIV disease or AIDS.

Participants organized issues raised in the brainstorming session under four general topics: continuity of service, cost of services, institutional capacity and leadership. These topics were then discussed in smaller topical groups.

Issues identified during the brainstorming session were:

- How can HRSA ensure that the State agencies maintain, as mandated by the CARE Act, level funding of local appropriated dollars? Some work group participants felt that their States might be submitting false “maintenance of effort” reports. The group recommended stronger government oversight, which should include audits by Federal agencies such as HRSA or the Office of Inspector General (OIG).
- Definitions and standardization of key terminologies (i.e., advocacy, unit of services) used by various planning councils are needed to avoid the exclusion of subpopulations from services or from representation on planning councils and in consortia.
- Monitoring tools should be developed to ensure that the affected population is receiving an appropriate share of funding for services.
- Use of the term “minority” groups all subpopulations into one category, resulting in the assumption that gay or bisexual men of color are solely African Americans. HRSA needs to help correct this misinformation and to expand the definition to include all gay and bisexual men of color, i.e., Latinos/Hispanics, Asian and Pacific Islanders, American Indians, and Alaska Natives.
- What is a consortium? What should it be? Guidelines on how a consortium should function and its relationship to planning councils and State AIDS planning need to be defined.
- Continuity of care must be addressed to foster maintenance and expansion of specific racial/ethnic organizations and programs serving gay men.

- The use of data based on cumulative rates of HIV infection should be eliminated. These rates misdirect services away from the populations who have large numbers of new, active cases. Agencies often use this approach to direct service funds away from gay and bisexual men of color toward populations that do not have large numbers of active cases.
- Organizational capacity of CBOs that serve gay/bisexual men of color must be enhanced.
- How will HRSA address the need for educating people who wish to serve on planning councils, but who may lack the sophistication and/or technical skills to do so? These individuals often can make meaningful contributions to deliberations about funding. Some examination of the dynamics of power—who has it, who won't share it—is needed. Efforts are needed to close the information gap between planning councils, affected populations, and CBOs.
- How do we provide services to gay and bisexual men of color without government interference in their daily lives? Many bisexual men have children and could very likely be separated from their families and children. Maintaining their confidentiality is key.
- How can existing organizations—both community-based and AIDS service organizations—build capacity and be strengthened to increase their effectiveness to manage Ryan White dollars?
- Continuity of care means keeping people in the “service loop”! The first point of entry into the health care system is generally through large well established organizations. In these institutions, because men of color often feel a lack of self-identity as gay or bisexual, they remain anonymous. Additionally, services from the larger institutions often do not meet their social/emotional needs, and they begin to look elsewhere for services in their communities. Unless there is a strong network of providers to ensure the continuum of care, they get lost or experience gaps in needed services. HRSA must assess how well advocacy programs are linked to service programs. Also, shorter targeted protocols are a possible strategy to track client flow among providers and to evaluate the community's level of knowledge about available service.
- Models are needed for services that empower communities of color. People of color may not access all of the services available through the full spectrum of CARE Act-funded services. HRSA can address the issue of appropriateness of services versus service capacity,

emphasizing qualitative evaluations and suitable quantitative evaluations to faithfully capture the nature and strength of these strategies. “Develop evaluation instruments that our population can use.”

- There needs to be an investigation of the representation of gay and bisexual men of color on planning councils and consortia, and legislative or administrative action should be pursued to remedy any lack of representation.
- Any effective evaluation plan must examine equity. How do we ensure equity in access to services, types of services, and quality of services?
- Service providers and policy makers need information on the factors that influence people’s choice of services at one site instead of another. A real difference exists between which services gay people use, depending upon whether they socialize within their racial context, or within the mainstream gay community. Without some way of measuring these differences, this will remain a hidden issue.
- How can CARE Act services be linked/or integrated with other services to create a “net” that will reach men who do not routinely seek care? Do these individuals use services at an institution which provides a variety of services or at single service sites?
- Many men of color who have sex with men may approach health care from the perspective of culturally-based holistic methods of treatment. HRSA should recognize and support programs and projects that are based on non-Western holistic models of treatment and therapies—those not solely based in biomedical applications. People may be more comfortable and satisfied with culturally appropriate healing practices, and appropriate methods should be identified to evaluate effective ways of drawing on these resources.
- Local rural agencies need to educate people at risk about the importance of seeking care and using it effectively. It is important to use people from local communities to advocate and administer services, to provide peer health education, and to use effective outreach (i.e., case finding) methods.
- There is a need to develop individuals and empower their communities to support physical health and spiritual growth. This includes addressing sexual identity and one’s place in the community.

- Overall community capacity must be analyzed. For instance, cost of services is different in different places. Wealthy communities are far more likely and/or able to diversify services than poor communities that must centralize services to meet their complex needs.
- Duplication of services is necessary for the development of minority organizations serving gay and bisexual men of color. Working linkages between gay and bisexual men of color CBOs and mainstream agencies also are necessary to develop agencies serving gay and bisexual men of color and to reach more people with HIV/AIDS. The protective attitude that exists between mainstream and minority service providers needs to be challenged if services are to be to open and accessible to everyone.
- The context and attitudes unique to services by and for gay and bisexual men of color make these services essential, and therefore not redundant. Such services increase choices in health care (the lack of choice is a point of contention for people who have few options). Choices will significantly improve the level of access to and retention in services.
- What obvious and hidden costs of "doing business" do small CBOs experience in providing services to special populations? If the CARE Act restricts administrative overhead, small CBOs will have difficulty providing services and sustaining their administrative and program development.
- Reimbursement payments from State governments often are slow or delayed. This results in a major burden for small CBOs.
- Funding to train family members in HIV/AIDS care is important to ensure that people living with HIV/AIDS can be cared for at home.
- Because many minorities use services at public health departments and clinics, linkages between these public agencies and community based networks of HIV/AIDS providers should be required. Health department services also should be culturally sensitive and competent.
- Often when people are seriously ill, they disclose their gay or bisexual identity. If the agencies serving them are not connected to their racial, ethnic or sexual orientation, this disclosure may create problems of confidentiality, isolation or alienation.
- When dealing with the dynamics of the "invisible" communities, policy makers have to continue supporting the specialty providers

who can effectively and appropriately address racial, cultural, ethnic, and linguistic issues. This support increases the likelihood of knowledgeable and acceptable service providers for people with HIV disease. Support for outreach also is critical.

- The impact of “health care reform” on the CARE Act and its potential effects on the gay/bisexual men of color population must be examined. What is the real issue: access or the ability to pay?

The brainstorming session resulted in this extensive list of issues, which the group used to set the agenda for the topic and racial/ethnic group breakout sessions summarized in the next section.

Reports from the Topic Group Sessions

The facilitators asked each topic group to discuss specific issues and identify priorities for action that would increase access to services for gay and bisexual men of color. They also asked each group to identify priorities for evaluating programs and providing technical assistance. The reports first list the evaluation and technical assistance priorities and then summarize the group discussion.

Group 1: Continuity of Services

Questions for Evaluation

Do specially-designed information, organizations, and resources improve access to care for gay and bisexual men of color?

- How do referrals occur and how can they be improved? What data on client knowledge, administrative procedures, and client flow need to be collected?
- How can different models of service delivery be evaluated?
- How do access-centered services and empowerment strategies reduce barriers to care for gay and bisexual men of color?
- Does training for cultural competency (client satisfaction, language skills, and experience with communities) lead to increased access?
- What qualitative methods, such as focus groups, and other methods have the potential to capture the nature and strengths of the strategies?

Technical Assistance Issues

- Capacity building for organizations and individuals that serve gay/bisexual men of color: treatment advocacy, services advocacy, and continuity of care skills (i.e., current case management models may not be appropriate).
- Training to improve mainstream service providers' ability to identify cultural sensitivity issues and resources associated with the empowerment of various populations, including immigrants.

Discussion

Continuity of services can only be ensured if there is a capacity to develop and deliver services. Most CBOs lack the infrastructure and the funding for essential staff and equipment required to stabilize programs. The ceiling on administrative costs imposed by the CARE Act generally undermines the funding support needed by minority CBOs. Neither planning councils nor State governments address the infrastructure needs of small CBOs that provide HIV/AIDS services. This issue must be addressed in concert with the continuity of services.

Gay and bisexual men of color find and use services in a variety of ways. Many come into the health care system through mainstream organizations, and generally learn of their HIV status through these organizations. Many gay and bisexual men of color learn of their HIV status at public health clinics and hospitals while seeking services for other medical conditions. In general, and particularly in large urban areas, these facilities operate outside of the HIV/AIDS service delivery network. Staff at testing and counseling sites too often inform clients of their HIV status, but do not encourage them to seek support from an HIV/AIDS network. Linkages must be established with these institutions to ensure that HIV positive clients are referred to an HIV/AIDS network. Hospitals (and some public health clinics) must develop discharge planning models to link seropositive clients with HIV/AIDS ambulatory care facilities. Individuals working in public health clinics and hospitals must be educated about the availability of CARE Act programs and the referral process for linking their discharge clients to these programs. Agencies must train their intake specialists to identify gay and bisexual men of color and to process their cases respectfully and confidentially.

Case management is the key to continuity of care. Well-trained and informed case managers can develop client plans and connect clients with appropriate services. After informing clients of their seropositive status, counselors should refer them to case managers who can place them in appropriate medical and support psychosocial services. Through case management, clients will have the support of someone knowledgeable about services and treatment options and the encouragement to stay in treatment.

Case managers working with gay and bisexual men of color ideally would be gay or bisexual men. In reality, however, this is not always possible. Cultural training, including awareness of issues and concerns of gay and bisexual men of color living with HIV/AIDS, can increase the

effectiveness of all case managers. As mentioned earlier, integrating the entire service system through formal linkages will reduce the chances that providers deny clients treatment or service. System-wide tracking or monitoring of programs must be developed to document a client's receipt of service from any and all providers in the network. Major health care institutions and small community-based providers must be able to share basic client information to verify that referrals have been initiated and that service has been rendered.

Safeguards, however, must be built into the system to restrict access to client data and ensure confidentiality. Agencies should develop policies and procedures to restrict sexual orientation information to physicians and case managers. The clients must be given the right to decide which providers will share this confidential information.

Group 2: Cost of Services

Evaluation Priorities

Questions for evaluation studies might include:

Does equity in resources allocation, both at gay and non-gay organizations, reduce the barriers to HIV/AIDS care? Does shifting the emphasis from AIDS to HIV increase client access to care and the quality of care and increased cost?

- Research on people of color populations
 - Health-seeking behaviors of gay and bisexual men of color
 - Behavioral intervention studies
 - Knowledge of the populations being served
- Cost of providing services may be greater for gay and bisexual men of color providers than non-gay providers, because additional points of entry into the medical system are needed.

Technical Assistance Issues

- Administrative and Infrastructure
 - Technical assistance to build CBO organizational capacity
 - Training providers regarding racism and bigotry
 - Development of culturally-specific infrastructures
- Accountability of maintenance of funds
 - Audit by government agencies (HRSA or OIG)

- Improvement of Title I and II integration (not duplicating, but improving communication)
- Reauthorization policy: role of consortia in State planning
 - Consortia must be integral part of the State planning for HIV

Discussion

Discussion in this break-out group identified as a concern the cost of developing and delivering services to gay men. Several participants cited instances where the cost of services may have appeared greater in the short term, but was necessary to address the complex issues surrounding delivery of services to gay and bisexual men of color. Some examples were: additional and multiple points of service within and outside of racial and ethnic communities; special efforts to increase use of services during the early stages of the infection and to reduce discontinued follow-up care; and the cost of small-scale community-based operations that have greater credibility among gay and bisexual men of color. In addition, if successful, the initial cost associated with early treatment may appear greater. A full analysis must consider cost over a longer period of time and the costs of inappropriate and delayed use of services.

In addition, participants cited the scant research available on the use of health services by gay and bisexual men of color. Such basic information about health seeking behaviors is essential to providing the context for cost of services analysis. Given these underlying factors, the participants considered evaluation studies crucial to determining whether the cost of services reflected patterns of increased use, more intensive use, and/or greater access to services.

Group 3: Institutional Capacity

Questions for Evaluation

- How can we facilitate agencies' efforts to respond to and serve the needs of gay and bisexual men of color? How can we best evaluate those agencies serving gay and bisexual men of color?
- How do organizations develop the capacity to deliver a continuum of care that is satisfactory and appropriate to the needs and concerns of gay and bisexual men of color?
- Does the involvement of gay men of color in decision-making processes increase access to care?

Technical Assistance Issues

- Assist gay and bisexual men of color in community organizations and agencies in applying for funds and effectively delivering services.
- Cross-training of service providers' administrative and clinical staff in the areas of substance abuse, mental health, clinical trials, support services, and volunteer recruitment and coordination.

Discussion

The gay/bisexual community is not homogeneous. There are significant social and cultural differences experienced by gay and bisexual men of color that influence how they perceive themselves and how they interact with the larger society. Gay and bisexual men of color generally identify with their racial or ethnic group first and often choose not to adopt the political or social values of the mainstream gay/bisexual community.

Most gay and bisexual men of color, as a result of racism and classism, remain hidden in their communities of origin, and do not distinguish themselves as a subgroup within the larger racial/ethnic population. This invisibility, coupled with racism and classism, becomes a significant barrier to planning and delivering health care. To reach the majority of gay and bisexual men of color who fall into this category, leadership must make a commitment to the HIV/AIDS community to resolve this dilemma. The first step is to solicit the participation of gay and bisexual men of color from racial/ethnic groups involved in CARE Act-funded programs. Representation from these groups can serve as a catalyst for developing sensitivity training programs to educate mainstream providers about the cultural differences to be considered as they provide services to these populations. Physicians and clinicians must be aware of and/or understand the distinctive cultural values and mores of their clients to establish trust with patients and earn their confidence.

Trust is fundamental to client relationships when providing services to gay and bisexual men of color. Clinical and front line workers must be sensitive to the concerns and issues of these groups, which may include creating environments that ensure respect for racial/ethnic differences and confidentiality of sexual orientation, as well as of seropositive status. In addition, the clients must be able to maintain their individuality.

Language continues to be a significant barrier to HIV/AIDS care for many gay and bisexual men of color. Health care systems must develop the capacity to provide interpreter services for all ethnic communities, which need to be culturally and linguistically sensitive to community differences. For instance, the diverse ethnic backgrounds of Latinos/Hispanics have to be considered as services are delivered to them. Using family members as medical interpreters is generally neither appropriate nor effective. This breaches confidentiality, and family members often lack the ability to translate important medical information critical to effective treatment and care. "Language pools" could be created for use by providers lacking bilingual capacity. All interpreters must receive training in cultural differences, issues, and concerns germane to the diverse ethnic populations.

In cities and rural areas with populations of people of color, efforts should be made to create racial/ethnic-specific CBOs to provide HIV/AIDS services to ensure cultural competency and linguistic capability. The need for these organizations is critical in racial/ethnic communities where there are high rates of HIV risk-related activities. Gay and bisexual men of color experience problems including poverty, homophobia, internalized homophobia, and substance abuse. Generally, people of color organizations are better equipped to address these issues than are mainstream organizations. The socioeconomic dynamics between minority groups are broad and complex, and racial/ethnic minorities must not be "lumped" together for the sake of political and organizational expediency. Thus, creating one or two organizations to fulfill the needs of all minorities is not realistic, nor is it likely to be effective.

Planning councils have used duplication of services as a factor in denying minority organizations funding in various service categories. Clearly, the cultural and language differences alone warrant the need for specific racial/ethnic providers. The extent of racial/ethnic diversity in most American cities, and in a significant number of rural areas as well, supports the need to have several providers offering similar services within the same geographic area. Racial/ethnic differences must not be devalued. Multiple points of access to health care and support services should reach minorities who presently feel alienated from HIV/AIDS services due to racial/ethnic issues and concerns. Many communities, however, do not have the resources to establish racial/ethnic-specific organizations that meet the needs of all affected populations. Therefore,

racial/ethnic competency and sensitivity must be developed in providers within existing mainstream organizations. As mentioned earlier, training in cultural sensitivity is a fundamental factor in addressing the needs of diverse communities. This training also must specifically include the issues and concerns of gay and bisexual men, and must integrate sensitivity into every aspect of service and personnel policies. Staffing to achieve sensitivity and inclusion of racial and sexual minorities must reflect the diversity of the population to which services are being delivered.

Formal agreements must be created to ensure that referrals are made and honored. No client should forego a service because the referring agency failed to initiate and to follow up a referral or document service delivery. Linkages among CARE Act-funded services must be formalized and understood by all providers. Case managers must be held accountable for the development of client plans, and for the implementation of such plans. All case managers must be trained in a HRSA case management protocol to ensure that the needs of clients are met. Evaluation tools must be created to monitor the quality and responsiveness of all vendors providing CARE Act-funded services, and to determine the competency of providers to deliver services and to meet the specific needs of their clients.

Group 4: Leadership

Questions for Evaluation

Choosing representation:

- How is indigenous leadership selected or identified to include affected, infected, and regional representation?
- How is nomination/appointment (including community endorsement process for representatives and alternates) handled?
- Are there qualifications based on community/population constituency and affiliation?
- Evaluations of different State laws impacting planning council/planning process (i.e., sunshine laws) are needed.
- Are there guidelines for community representatives to include demonstrated knowledge of the HIV/AIDS health care system?
- What are the qualifications necessary for appointments?

Supporting representation:

- Orientation/training. How does orientation and training about planning council and consortium participation impact effective representation of gay and bisexual men of color?
- Lack of public policy/advocacy positions funded to represent these communities.
- Reimbursement for planning council, employment of advocates, and other advocacy activities.
- Gay/bisexual men of color services and leadership should be evaluated and assessed for uniqueness/specificity of services.

Technical assistance issues:

- Support the development of caucuses and advisory committees of gay and bisexual men of color.
- Develop mechanisms to encourage gay and bisexual men of color living with HIV/AIDS to seek services at an early stage of illness.
- Monitor providers, especially those in areas where few exist, for the quality of care provided to gay and bisexual men of color.
- Encourage planning council financial management systems, human management systems, and development and grant writing assistance to CBOs.
- Support meetings between governors and/or mayors with planning councils and consortia to reinforce the importance of HIV-related services.

Discussion

If gay and bisexual men of color are to increase their access to health care and support service delivery systems, they must participate more actively in the process that determines which services are important and which providers should be included in the pool of care givers and service providers. Nationally, participants stated that gay and bisexual men of color are not participating in planning councils or consortia in a percentage reflective of the number of infected persons from their communities. By and large, the group felt that heterosexuals and white gay men comprise the majority of planning council membership. The racial/ethnic minority representatives on councils neither actually nor adequately represent the populations most affected by the epidemic. In fact, the presence of gay and bisexual men of color on planning councils and in consortia was observed to be minimal or non-existent.

It is a truism that homophobia and racism contribute to the reluctance of many individuals to participate in any public forum as self-identified gay or bisexual men. Planning councils and consortia must create safe environments in which gay and bisexual men may effectively contribute to decisions about funding and service development without undue attention to their sexual orientation. Native Americans and Asian and Pacific Islanders expressed their particular concerns about this issue and how it affects participation in isolated areas and in very close-knit communities.

A recommendation was made that HRSA investigate the manner in which citizens are chosen to participate on planning councils and in consortia. At present, State and local government officials determine the composition of these bodies. The group felt, however, that steps must be taken to ensure that the demographics of the epidemic are reflected in the composition of planning councils and consortia.

Another recommendation was that HRSA should investigate local and State laws that negatively influence the composition and work of planning councils and consortia and, specifically, determine what criteria may directly or indirectly exclude membership. Although HRSA cannot change State laws, the group felt that penalties should be established for planning councils or consortia that violate the spirit of the CARE Act.

The group also noted that occasionally persons selected to represent racial/ethnic populations are not actually familiar with the groups they are expected to represent. To avoid this, the work group recommended that representatives be solicited from the communities to be represented. Advocacy groups and providers must be among the groups endorsing the candidates selected. Their confirmation will help ensure that the planning council or consortia members have direct knowledge, support, and confidence of the groups they are expected to represent.

Some people of color are unable to participate in planning councils and consortia because they lack the education or job flexibility. Provisions must be made to address the need for orientation and training for novice members of planning councils and consortia; to participate meaningfully they need to have a thorough knowledge of the planning body's history and procedures. Because HIV/AIDS care often depletes the savings of people living with this illness, it is recommended that funds be set aside to cover the expenses related to participation on planning councils and consortia by persons living with HIV. These funds should be used for transportation, mailings, food, and possibly time lost from work.

Some planning councils may need to reschedule their meetings to accommodate members who work in positions that prevent them from participating in other activities during business hours. Evening and weekend meetings may be more convenient for these individuals.

Areas of the country with only a few gay and bisexual men of color face additional problems. In those areas, the pool of men who have HIV/AIDS and who are available and willing to participate in planning councils and consortia is small. Policies must be flexible to promote broad participation. For example, accommodation should be made for persons who must miss meetings or who send alternate representatives because of employment or health. In States where "broad-based laws" tend to discriminate against or disenfranchise gay and/or bisexual men, HRSA must advance administrative policies and guidance that ensure that gay and bisexual men of color are not systematically omitted from participation in decision-making bodies.

HIV/AIDS services and leadership specific to gay and bisexual subpopulations should be evaluated using criteria that assess the uniqueness and specificity of services. Each community service must be evaluated to determine if, or why, "duplication" of service applies. In communities where minorities have experienced institutionalized discrimination and have been denied access to health care, members may choose not to access services from mainstream, white service providers. Perhaps the most effective way of connecting disenfranchised people with services may be to establish racial/ethnic institutions that can overcome discrimination and offer a more receptive environment. The key is to create as many points of access as possible.

The term minority is generally understood to refer to African American and/or Latino/Hispanic. This doesn't take into consideration other racial/ethnic populations, and fails to recognize the needs of Asian and Pacific Islanders and American Indians/Alaska Natives. In all correspondence from HRSA, emphasis must be placed on all racial/ethnic groups that comprise the specific underserved or unserved populations in an EMA or State.

All service categories are not applicable to all racial/ethnic groups. States must be made aware of the need to conduct user assessment studies to determine which services affected populations will want to access. Some gay and bisexual men of color may prefer to use traditional medicines or treatments. A drug assistance program that does not include alternative therapies and treatment may give the impression that

the health care system does not value the lives of these clients, and could also result in unnecessary deaths.

Technical Assistance Discussion

Planning councils and consortia must begin to provide "space" for the development of caucuses and advisory committees of gay/bisexual men of color. The groups will help their communities reach consensus around services that are important, and also will provide a vehicle for training future members of planning councils and consortia.

Gay and bisexual communities of color have developed few grassroots advocacy organizations because civil rights issues impact them within the context of their racial/ethnic experience rather than their sexual orientation. Therefore, few such communities have developed leadership in these areas. Creating culturally sensitive services from the perspective of sexual orientation becomes a difficult matter in communities with a less visible population of gay and bisexual men of color. Often, men seek services far from their communities or refuse to seek services at all until they reach the end stage of AIDS. Mechanisms must be developed to encourage these men to seek services early. Local institutions must educate clinical and support staff about the need for, and the importance of, creating a safe place for all to use services. The stigma associated with HIV/AIDS is amplified when health care providers fail to show compassion for all of their clients, regardless of race, ethnic background, and sexual orientation. The work group recommended that HRSA provide technical assistance in this area (development of community organizations and leadership) in the form of workshops that train and monitor providers who must operate in multi-cultural communities, particularly where there are few, if any, population-specific health care or support service providers.

Many new CBOs need technical assistance in the areas of financial management systems, human resources management and development, grant writing, and conducting effective outreach efforts. CARE Act funds are inadequate to stabilize the infrastructure of CBOs that lack personnel or volunteers with fund-raising and development experience. CBOs would greatly benefit from any and all technical assistance HRSA could provide in these areas. CBOs developed to meet the needs of gay and bisexual men of color generally are very small, and are only able to provide a limited number of services to a very small number of clients. Planning councils lack the motivation to invest in these population-

specific organizations. Without encouragement from HRSA, planning councils will not adequately address this issue.

Few, if any, governors and/or mayors meet with planning council and consortia to keep abreast of developments related to HIV/AIDS services and the state of the epidemic. Local executives should be encouraged to have occasional meetings with planning councils and consortia. Their visible support would give clout to the organizations and reinforce the importance of the work of planning and coordinating groups.

Reports from the Racial/ Ethnic Group Sessions

Group 1: African American

Members of the African American break-out group reported both positive and negative health care experiences. Their discussion included a wide range of perceptions and experiences. At one end of the continuum were resourceful individuals who are able to find and maintain satisfactory relationships with providers (often aided by friends). In contrast were unsatisfactory experiences of individuals who encountered acts of bigotry, institutional racism, and unnecessarily cumbersome organizational procedures.

Gay and bisexual African American men, a diverse group, find a wide range of circumstances when they seek HIV care. Further, sexual orientation issues manifest themselves in various ways within the African American community. Gay and bisexual men who are African American seek out and use services from various agencies within and outside their communities. Some prefer local providers who permit them to maintain their sexual anonymity while they receive the care and the support they need. In some locales, gay and bisexual men design, run, and staff agencies where men who have sex with men can be comfortable receiving services and being public about their identity.

Because the African American gay and bisexual community is diverse culturally, socioeconomically, and linguistically, planners and providers must offer as many points of access as possible. Further, gay and bisexual men of color often have complex psychological and social backgrounds. It is important for African American providers serving gay and bisexual men to develop and maintain linkages with certain essential organizations. This will facilitate timely and appropriate referrals to clients who wish to seek services from population-specific providers.

Most organizations serving African American gay and bisexual men lack adequate resources to stabilize their infrastructures. Many operate with limited human resources (i.e., full-time financial, payroll, and administrative officers), and support mechanisms (e.g., computers,

copiers, and office space), to provide diverse or comprehensive services. These organizations would benefit from technical assistance in developing fiscal management systems, business plans, office procedures, and board of directors' development and training. Such assistance is essential for small CBOs to compete successfully with larger, well-established majority agencies.

A troubling observation among many African American gay and bisexual men is that mainstream gay AIDS service organizations often profess to provide services to gay and bisexual men of color when, in fact, they provide few or no services. The African American participants voiced a concern about this perception. Now that the demographics of the epidemic are changing, mainstream gay AIDS service organizations are beginning to compete with small agencies controlled by and designed for racial and ethnic clients. It was recommended that HRSA develop some guidelines to ensure that population-specific organizations are not eliminated from the competitive process. Funds may need to be targeted specifically to these organizations to ensure participation in HIV/AIDS service delivery. As is the case with other groups of gay and bisexual men of color, representation by African Americans on planning councils and consortia may not reflect their numbers within the affected HIV community. Administrative intervention by HRSA may help ensure that "community" representation on planning councils and consortia mirrors the spirit of the CARE Act.

Group 2: Asian and Pacific Islander

Generally, Asian and Pacific Islanders (A&PIs) have been left out of the planning, designing, and administration of HIV social and medical services programs—an experience shared by A&PI gay and bisexual men. This exclusion is evident in their lack of representation on planning councils and consortia. Without a visible and constant presence on such planning and decision-making bodies, the issues and concerns of A&PIs will continue to be unmet. A&PIs must be full participants in planning councils and consortia to effectively ensure the delivery of services to their communities. The number of A&PI professionals that volunteer with AIDS efforts is small, and the clients they serve are diverse in cultural background, language, and literacy.

Adequate funds must be targeted to develop and sustain viable operations and infrastructures to ensure the delivery of comprehensive and reliable services to A&PI gay and bisexual men. Overburdened staff

resources undermine the quality and quantity of services available for clients. Unlike larger well-funded organizations that can leverage target funds, small Asian and Pacific Islander agencies too often find small funding levels useless. A&PI access to services through mainstream organizations does not meet their needs. In addition, cultural factors related to health seeking behavior may delay use of services by A&PIs with HIV. These problems underlie the desire of Asian and Pacific Islanders to have a greater role in responding to HIV in their own communities.

As in other communities, A&PI gay and bisexual men generally do not openly identify themselves as gay. They prefer to stress the ethnic/racial identities that connect them with supportive communities rather than the sexual identities that may isolate or alienate them from their families and communities. When gay and bisexual A&PIs have participated in planning councils and consortia, they have not found these environments particularly supportive or reassuring. Planning councils and consortia must take steps to empower representatives from people of color communities to foster their effective and meaningful participation without compromising their identities within their communities.

The Asian and Pacific Islander community is comprised of many ethnic groups, who often speak different languages and practice distinctive traditions. Providing services to these groups means that providers must establish linkages with the various local communities. These connections will ensure that A&PIs have access to interpreters and other culturally appropriate resources. In most instances, trained adults are needed to serve as interpreters or advocates in important medical conversations between physicians and patients. It is inappropriate to use children, relatives, and support staff as interpreters for such important and intimate matters.

To ensure the well-being of A&PIs living with HIV, they must be empowered to take an active role in their health care. They must be enlightened about the need to ask questions of physicians regarding treatment and protocols, and must also be encouraged to study and participate in individual and group exchanges about treatment and provider options.

Because many Asian and Pacific Islander communities include recent immigrants, they must be empowered with information about modern medicine and therapies. They must be educated about the health care

system and encouraged to work with case managers to learn how to access services. When they have difficulty recruiting patient advocates or case managers from these populations, planning councils and consortia must target and train “para-professionals” from these communities to assist case managers with connecting clients to necessary services. Although mainstream providers have generally been receptive to A&PIs, many A&PIs do not feel comfortable and prefer to obtain services within their own communities. This is particularly true for many who would prefer to use traditional therapies and treatments rather than modern medicines. It is recommended that HRSA join A&PI advocates in securing funding for traditional therapies and treatments.

Asian and Pacific Islanders must have the support and encouragement of all levels of government to help develop local organizations into effective agencies capable of responding to the HIV epidemic. Culture-specific organizations have credibility within their communities and have the potential to address the needs of their members. Policies and procedures implemented by local, State, and Federal agencies can help actualize this potential. Support for work groups to teach A&PIs how to access services within and outside their communities, how to conduct outreach, and how to provide peer education must be provided.

Many Asian and Pacific Islanders view clinical trial participation as an inaccessible route to obtaining HIV services. Examples of successful A&PI participation in clinical trials will pave the way for others to use this route as a means of obtaining vital primary care and support services they may otherwise miss. Furthermore, because the metabolism of many A&PIs is “out of sync” with Western culture, it is important to know how Western therapies and vaccines react to the systems of A&PIs.

Group 3: Latino/Hispanic

Organizations serving Latino/Hispanic gay and bisexual men often face greater scrutiny by decision-makers and funders than do mainstream service organizations. This is unfair, because these organizations frequently lack the infrastructure and level of volunteer support that permits most mainstream AIDS service organizations to provide a higher and more complex level of service. Also, program evaluators fail to take into account the vast cultural, racial, ethnic, and social diversity that exist in the Latino/Hispanic community. Attention must be given to conducting research projects to determine how Latino/

Hispanic men, particularly men who have sex with men, access services.

Latino/Hispanic persons from primarily rural countries often lack experience with and trust of Western medicines and services. Health and well-being are tied to the social order of their countries of origin—traditions which continue in this country. Yet, providers often have an implicit expectation that a patient disavow traditional therapies as a condition of receiving Western medicine. Providers serving this population must be educated in the cultural dynamics of these communities.

Many clients may become more receptive to Western treatment if it can be integrated within traditional therapies and treatment. Health care professionals must be educated about the role traditional medicines play in these communities, and the integral role of traditional healers in many Latino/Hispanic communities. Names such as *curandero(a)*, *sobaders*, and *el yerberos* are familiar terms that many Latinos/Hispanics used for “traditional healers.” Models must be developed to permit reasonable mingling of these two treatment perspectives to ensure that clients adhere to the instructions of health care professionals.

To facilitate access to services, organizations must either hire staff from these communities or support population-specific organizations. When clients are not prepared to integrate into the traditional care/support delivery systems, appropriate referrals must be available to ensure that the client receives competent and responsive assistance. Clients must not be left to “fend for themselves,” but must be procedurally connected to the receiving providers; i.e., formally documented procedures must be established to ensure that clients arrive at the place of referral. Without adequate client-flow systems, individuals will be lost and may not be seen again until they have very complicated health problems.

Systems must be developed to provide effective and efficient HIV outreach in rural areas where services may be great distances from the client(s). Many rural residents with HIV consider services currently available to be lower quality, culturally incompetent, and linguistically inappropriate. To improve access in these areas, there also should be support for mobile high quality health services.

Studies of effective service models must be conducted by HRSA so that these models can be shared with providers in other regions of the country. Programs and projects demonstrating cultural competency must be duplicated and/or modified as appropriate. Many bisexual men are

married with children. These families must be provided services as a family unit, and agencies must adapt existing models or develop new models to address the dynamics and needs of these families. Appropriate mental health services are a critical factor in keeping family units together as they cope with HIV/AIDS. This is particularly true for substance abusers, who require intensive treatment and support. Discharge planning protocols also must be developed to link ex-offenders to the health care and support service systems. Without effective linkages, clients will be lost to the system.

Group 4: American Indian/Alaska Native

Cultural competency is a central part of health care delivery among American Indians and Alaska Natives. Like other racial/ethnic groups, they have a long history of traditional medicines and therapies, and a significant number either prefer traditional treatments to biomedical therapies or seek to combine the two. Without flexibility in this area, many American Indians and Alaska Natives may continue to refuse early intervention services. Physicians and other providers must be willing to acknowledge the role of traditional healers in American Indian/Alaska Native cultures and, when necessary, to enjoin the services of healers. The definition of service must be expanded to include cultural activities that are central to the social, emotional, and spiritual practices of seropositive First Nation people. Yet, CARE Act planning councils and consortia have not provided funding for cross-cultural approaches to health care.

American Indian and Alaska Native advocates are seeking to expand the pool of outreach workers who are knowledgeable about the community. Empowering traditional healers with HIV/AIDS knowledge can have a profound impact on outreach efforts to identify people who practice high risk activities. Peer education is viewed as another pivotal tool in empowering persons with HIV/AIDS to take control of their health.

The social policy and procedures of this country continue to place great significance on the "blood quantum" of American Indians and Alaska Natives. Those with HIV are often caught in paradoxical situations. People who cannot prove their lineage will be denied social and health services targeted to Federally-recognized tribes. At the same time, individuals who seek care outside of the Indian Health Service (IHS) are often refused because IHS is presumed to be solely responsible for their care. This exclusion includes CARE Act-funded services. Often

agencies are reimbursed for services and treatment provided to unenrolled people; this must change. American Indians and Alaska Natives are looking to HRSA to initiate the change.

While First Nation people reside in every State and travel between urban and rural centers, CARE Act Title I funds do not benefit the 50 percent of Native people who live outside eligible metropolitan areas, and many of them with HIV do not have access to services they need. Frequently, the boundaries of American Indian/Alaska Native communities cross the jurisdictions established for the distribution and administration of CARE Act services. HRSA must develop policies or guidelines that will remove this barrier to services. American Indians/Alaska Natives also are asking HRSA to broaden the definition of community to encompass all individuals in need of service. Because gay and bisexual men in these populations generally do not self-identify, providers must be trained to accept clients as they present themselves. Inaccurate labeling turns attention away from providing services and focuses attention on data collection activities.

Closing Observations

Numerous common themes were expressed in all the communities of color discussions: affirmation of their racial and ethnic identity and of the values inherent to their community of origin; the feeling of empowerment gained through self-identifying as gay, bisexual, or as a man who has sex with men; the fundamentally inadequate and unstable nature of health care and social services within communities of color; the need for investment in infrastructure development within organizations specifically developed to serve people of color; the need for multiple points of access to effectively provide services to these diverse communities; the continuing discrimination and poverty that undermine well-intentioned HIV policies; and the desire for policies that affirm and promote the ability of gay and bisexual men of color, when given an equal opportunity to fairly compete for funding, to provide for their own communities.

Summary

After the small group discussions, the entire work group reconvened for group presentations to discuss the racial/ethnic sessions. During the roundtable discussion on the results of the racial/ethnic sessions, however, only persons who participated in the sessions could make changes to the list of priorities. Other members of the group were restricted to asking questions or sharing anecdotal information.

Following these activities, the work group was joined by invited guests, including Federal government employees, representatives from national advocacy groups, and other interested parties. Various questions and concerns about the purpose of the work group and the priorities they identified were raised and discussed.

Appendix A-1

BARRIERS TO RYAN WHITE HIV CARE FOR GAY AND BISEXUAL MEN OF COLOR:

A WORK GROUP

August 5 - 6, 1993

AGENDA

Thursday, August 5

- | | |
|-------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| 8:30 - 8:45 am | Welcome and Introductions
(<i>Moses Pounds</i>) |
| 8:45 - 9:15 am | Discussion of Work Group Objectives and Logistics
(<i>Moses Pounds</i>) |
| 9:15 - 9:45 am | Work Group Discussion of Barriers to Access Issues
(<i>Moses Pounds and Christopher Bates</i>)
"Getting To, Getting In and Getting Respect" |
| 9:45 - 10:00 am | Break |
| 10:00 am-12:30 pm | Identification of Barriers to Care Issues for Break-out Groups and Assignment of Participants to Break-out Groups (<i>Christopher Bates</i>) |
| 12:30 - 1:30 pm | Lunch |
| 1:45 - 5:00 pm | Reconvene in Break-out Groups to Design Evaluation Studies |

Friday, August 6

- | | |
|-------------------|-----------------------------------------------------------------------------------------------------------------------|
| 8:30 am - 2:30 pm | Break-out Groups Continue Deliberations
(<i>Participants and Staff</i>) |
| 3:30 - 5:00 pm | Report of Break-out Groups' Draft Evaluation Studies (<i>Federal and non-Federal HIV/AIDS agencies will attend</i>) |
| 5:00 - 5:15 pm | Closing Remarks and Departure |

Appendix A-2

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